Written evidence submitted by Alzheimer's Research UK

About Alzheimer's Research UK

Alzheimer's Research UK is the largest charitable funder of dementia research in Europe. Our focus on research means that we can channel our expertise and energy into catalysing scientific efforts in the UK and across the world. We are currently funding £39 million in world-class science at leading universities and research institutions and to date have funded £143 million in research projects.

Alzheimer's and other dementias are one of the UK's leading causes of death and with no treatments to slow, stop or cure them, they are diseases that no-one has yet survived. Not only does this cause harm and heartbreak to millions of families, but it is completely unsustainable for our health and social care system, costing the economy £26bn a year.[1] The majority of dementia costs per year are due to informal care at £11.6bn, with social care costing £10.3bn, and healthcare costing £4.3bn, this is expected to rise to £55bn a year by 2040 [2].

However, we are committed to changing that. Backed by our passionate scientists and supporters, we are challenging the way people think about dementia, bringing together the people and organisations who can speed up progress, and investing in research to make these breakthroughs possible.

Our mission is to bring about the first life-changing dementia treatment by 2025. Our research strategy is targeted to deliver research that offers the most potential for health benefit, including:

- Accelerating discovery science, including as a founding partner of the UK Dementia Research Institute, the country's largest ever dementia research initiative.
- Driving international early-stage drug discovery to translate promising developments in the laboratory into transformational treatments.
- Co-ordinating global efforts to detect the diseases that cause dementia at their earliest stages when treatment is more likely to be successful.

Contact us

We would be happy to discuss any of the issues raised within this submission in more detail. Please contact us at policy@alzheimersresearchuk.org.

1. The need for earlier, more accurate dementia diagnosis

Earlier, more accurate diagnosis of dementia and the underlying causal disease(s) is crucial to deliver better outcomes for patients and enable breakthroughs in research that could deliver new treatments. It helps patients get access to the care and support they need to plan for their future and gives them the opportunity to participate in clinical research, improving the chances of success in trials for potential new treatments.[3]

Evidence suggests that dementia is more likely to be treatable at an early stage as many of the changes in the brain associated with dementia can happen as many as 10-15 years prior to the onset of clinical symptoms. Despite this evidence, and increasing access to better diagnostic tools, most people living with dementia are only diagnosed when they or a loved one notice the symptoms associated with it, such as memory loss.

The primary focus of current drug development is on delivering a disease-modifying treatment for Alzheimer's disease, the most common cause of dementia, in its earlier stages. The progress of this research is being slowed down by a lack of early and accurate diagnoses which makes it challenging to find suitable candidates for clinical trials.

Unless we transform dementia diagnosis, it will be too late for many patients to benefit from new treatments. This is more pressing than ever, as the first potential disease-modifying treatment for Alzheimer's has been approved by US regulators and is currently being reviewed in the UK and Europe. If it is approved, it will likely be available to patients in the UK in the next few years.

2. Long-term lack of capacity in the dementia diagnosis pathway

Not having a dementia diagnosis has a broader impact across the health system. Dementia cost hospitals £2.7 billion in 2017-18 compared to £1.2 billion in 2010-11, and 90% of those costs came from emergency admissions, many of which were potentially preventable[4]. Emergency admissions are likely to be even higher for people with undiagnosed dementia, who won't be getting the care and support they need to manage their condition and the impacts for their wider health.

Most dementia diagnoses are made by memory clinics. The 2019 national memory service audit found huge variation between these clinics: the average waiting time from referral to diagnosis was 13 weeks (with waiting times varying from 3 to 34 weeks), and only 26% of patients were diagnosed within England's national target of 6 weeks.[5]

Looking at CT and MRI diagnostics specifically for dementia, there were already considerable waiting lists pre-pandemic. In the 2019 memory service audit, scan waiting times were highlighted as a key barrier to meeting the 6-week pathway. This was exacerbated by a lack of neuroimaging capacity, with 60% of memory services unable to view brain images from scans as they do not have access to the required imaging systems (PACS).[6]

There is also a significant capacity issue with tests used for the more specific diagnosis of Alzheimer's disease, rather than dementia more generally. A 2021 report from Alzheimer's Research UK and the Royal College of Psychiatrists found that just 6% of psychiatry services could fully meet the current NICE guidelines regarding accessing further biomarker and diagnostic tests (FDG-PET and CSF) for Alzheimer's disease.[7]

3. COVID-19 has exacerbated delays and backlogs in dementia diagnosis

The full scale of the impact of the pandemic on dementia diagnoses is difficult to assess due to the limited availability of data. However, **delays have worsened at key stages along the diagnosis pathway from fewer referrals and assessments to a backlog of 'missed' diagnoses and longer waiting times to access essential diagnostic tools.**

People concerned about their own memory, or that of a loved one, typically speak to their GP in the first instance. After conducting an initial assessment, the GP may then refer them on to a specialist setting such as a memory clinic for further assessment and diagnosis.

3.1. Referrals and assessments

Many people did not want to see their GP during the pandemic because they were worried about becoming infected with covid or were concerned about putting too much of a strain on the NHS. Some were isolated and did not have anyone to help them recognise they needed a diagnosis, and as it is difficult for people to discuss their symptoms remotely, a reduction in face-to-face appointments will have also had an impact on referrals to memory assessment clinics. In addition, variations in the availability of memory clinics, with some open and others closed, also meant fewer referrals could be made than before the pandemic.

Public Health England estimate a backlog of approximately 35,000 people aged 65 and over waiting for a dementia diagnosis, based on the number of missed dementia diagnoses up to summer 2021 when compared to previous years.[8] This is likely to be a considerable underestimate as it does not include people under the age of 65 (those with young onset dementia), the months since June 2021 or the third of people living with dementia who never receive a formal diagnosis.

Data from NHS England show that while the national ambition to diagnose two thirds of those estimated to be living with dementia has been consistently met since July 2016,[9] the diagnosis rate for those aged 65 and over dropped from 67% at the start of 2020 to 62% in September 2021.[10]

Another reason for the lagging dementia diagnosis rate is the limited access to diagnostics, particularly structural imaging capacity (CT and MRI scans). From February 2020[11] to September 2021,[12] the proportion of patients waiting more than six weeks to access CT and MRI scans increased from 2.1% and 2.6% to 18% and 23%, respectively.

During the pandemic, memory services were advised that *"if further investigations, e.g. neuroimaging, are required to establish the subtype but are not available then it would be acceptable to give a working diagnosis of unspecified dementia whilst awaiting further investigations."*[13] Not only does this add to the current bottleneck for neuroimaging services, but unspecified dementia diagnosis can directly affect the type of care and post-diagnostic support a patient receives e.g. in terms of accessing potentially important prescription medication.

4. Addressing long-term needs and the impact of the pandemic

The backlog in dementia diagnostic services has been exacerbated, not created, by the pandemic. Services within the NHS are aware of the need to address these backlogs, but they can't do this without more capacity and financial support.

While the one-off investment of £17 million announced by the Department of Health and Social Care (DHSC) in March this year[14] is welcome, it is nowhere near enough to address the backlog. DHSC must carefully and transparently monitor this investment's implementation and its success towards restoring the dementia diagnosis rate, so that in the likely situation that further funding is required, this can be calculated based on patient need and provided without delay. Similarly, the £375 million pledged in the autumn Spending Review to help clear backlogs throughout the NHS is welcome but we estimate that the cost of clearing the backlogs for dementia alone would be more than £300 million.[15]

As there was not enough capacity in dementia diagnosis even before the pandemic, both long-term structural solutions and more immediate interventions will be needed to address the backlog. The government and health system need to invest in the right workforce, infrastructure, and training for diagnosing dementia, including improving structural imaging capacity and access to further biomarker and diagnostic tests (FDG-PET and CSF).

4.1. The backlog cannot be tackled without sustainable, long-term reform of dementia diagnosis

It is vital that the Government's new Dementia Strategy looks beyond restoring services to pre-pandemic levels and sets out an ambitious plan to transform dementia diagnosis, backed by significant long-term investment.

The areas that require investment and attention to deal with the backlog (such as workforce, diagnostic infrastructure, and pathway reform), are the same as those that need to be addressed if we are to meet challenges such as an ageing population, existing structural barriers to improving diagnosis, and preparing the health system for the arrival of the first disease-modifying treatments:

- The NHS should invest in improving structural imaging capacity, including picture archiving and communication system (PACS), so that memory clinics can offer access to scans in line with NICE guidelines.
- The NHS should invest in improving patient access to FDG-PET and CSF tests for the diagnosis of Alzheimer's disease, in line with NICE guidelines.
- The NHS should mandate a national audit of all specialist dementia diagnostic services, beginning with a long-term commitment to a regular National Memory Clinic Audit.
- NICE should develop national clinical guidelines on the diagnosis, treatment and follow-up of patients living with Mild Cognitive Impairment (MCI) to support a transition from diagnosing in the dementia stage of Alzheimer's disease to diagnosing in earlier stages, including MCI, to which the current guidelines do not apply.[16]
- The NHS must plan for the future, scoping out short-term as well as long-term needs, and investing in infrastructure, resources and clinical workforce to build diagnostic capacity in preparation for the arrival of future disease-modifying treatments.[6]

- The health community should foster interdisciplinary collaboration between sites that already use molecular diagnostics, to increase relevant expertise across the country and develop a network of initial sites capable of delivering disease-modifying treatments in the short to medium term.
- The health community should evaluate, and where appropriate, support the potential of innovative service models, such as Brain Health Clinics, to offer a new diagnostic pathway.

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